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Daring to tell: the importance of telling others about a diagnosis of dementia

Abstract

Learning to live with a diagnosis of dementia is a complex process. Being able to talk about the diagnosis to others represents a major challenge for some people with dementia. This study explores the experiences of people with dementia, and members of their families, around the task of informing others during the six months immediately following their diagnosis of dementia. Five people with dementia living in the community, and their immediate family members, were recruited into an ethnographic study. Data were collected through recorded interviews and participant observation, and were analysed through a grounded theory method within a continuing iterative process. Findings suggest that participants recognised the need to tell others about their diagnosis but these conversations were difficult to initiate and manage, and hindered the processing of emotions. Findings are discussed in relation to implications for practice. .

KEY WORDS – community, counselling, dementia, diagnosis, early stage, emotion, ethnography, grounded theory, identity, narrative, qualitative research, relationships, self

Introduction

There is a growing body of evidence that supports the notion that people with dementia want to know the truth about their diagnosis (Wilkinson and Milne 2001; Pratt and Wilkinson 2001), with Elson (2006) reporting that that most (86%) of the adults attending a clinic to investigate memory complaints wanted to know the potential cause of their problem and 69% of them wanted to know even if that diagnosis turned out to be a form of dementia. Diagnosis is often experienced as confirmation of assumptions of both the person with the diagnosis and their carers (Derksen et al, 2006).

Receiving the diagnosis is the beginning of the journey of integrating the illness into everyday lived experience of coping with the condition (Cayton 2004). The impact of receiving a diagnosis of dementia, on sense of self, emotional well-being, and relationships with others has been documented in many studies (Clare 2002; Clare 2003; Harris and Sterin 1999; Preston, Marshall and Bucks, 2007; Werezak and Stewart 2002, Wolverson, Clarke, and Moniz-Cook, 2010). Systematic reviews of qualitative studies of the experience of living with dementia (Bunn et al., 2012; Steenman et al., 2006) have confirmed the robustness of these themes across a substantial number of studies. Phinney (1998) summarised the complex and fluctuating experience of people who had recently received a diagnosis of dementia as a process of oscillating between two poles: 'being unsure', and 'trying to be normal'. Pearce, Clare and Pistrang (2002) observed that people diagnosed with early dementia found themselves forced to construct a new sense of self, in the context of social interaction with others. In order that this new identity of self could be reached, a 'delicate balancing act' needed to be maintained, between wishing to maintain an existing sense of self and the acknowledging of the need for reappraisal and reconstruction. In terms of Sabat's (2001) use of self-theory to make sense of patterns of social interaction in people diagnosed

with dementia, a new attribute (the diagnostic label) has to be added to the existing self-definition of the person. Frank (1995: 55) suggests that ill people 'learn by hearing themselves tell their stories, (and) absorbing others' reactions'.

For people with dementia, their family members and carers, the task of conveying information about the diagnosis to other people within their social networks, represents a crucial aspect of the work of coming to terms with the illness, and developing a new self-narrative. Issues associated with the activity of telling have been highlighted in several studies. Phinney (2002: 340) suggests that the fluctuating nature of dementia means that the 'dementia story is inherently and fundamentally unknowable and untellable'. Phinney (2002) adds it is also a story that is impossible for the storyteller to give alone, because it is jointly lived, so it is inevitable that others will join in the telling. Werezak and Stewart (2002) described two factors that were particularly salient in relation to the decision of whether to tell or not – how people might act if they knew, and how people had reacted when they had known of the participant's initial memory loss. Langdon *et al.* (2006) found that participants in their study were reluctant to share their diagnosis with people outwith their 'private inner circle' for fear of being misunderstood. In contrast, McRae (2007) found that that only one of the participants in her study hesitated in telling others their diagnosis, while five told the people they thought 'should' know, such as friends and family, while two went out of their way to tell others.

The issues and dilemmas associated with the process of telling other people about a diagnosis of dementia are of additional interest because they represent a significant arena for support, facilitating and coaching on the part of nurses, doctors, clergy and other practitioners who may be professionally involved with a person with dementia, their family and carers. The challenge of disclosure provides opportunities for such practitioners to use counselling skills to enable people with dementia, and those around them, to explore the emotional

significance and impact of the diagnosis and the illness, and to rehearse strategies for how best to disclose the diagnosis to others (McLeod and McLeod 2011).

The aim of the present study was to explore the ways in which people with dementia, and those close to them, negotiated the task of disclosure of the diagnosis, through a six-month period following formal confirmation of the diagnosis.

Methods

The data reported in this paper are taken from a larger study which is reported in full elsewhere (Weeks 2006). This study took place in mid-Scotland within one Health Board area that encompassed both urban and rural environment. A focused ethnographic approach was adopted, based on collection of data through selected episodes of participant observation and unstructured interviews with relevant key informants (Muecke, 1994). We utilised these methods as a means of developing a multi-faceted understanding of the experiences of five families as they came to terms with a diagnosis of dementia. Each family included one member who had been diagnosed with early Alzheimer's disease, and had been prescribed with cholinesterase inhibitor medication. Contact with the research project occurred within nine days of the diagnosis. Ethical approval for the study was received from both the Health Board Local Research Ethics Committee (LREC), and a University Research Ethics Committee. Ethical consent was formally elicited from all participants in the study. Because of the length and intensity of the data collection, a procedure of process consent was used at each meeting to check on participant acceptance of data collection (Dewing 2002). Recruitment of participants into the study was initiated by the consultant psychiatrist responsible for the care of the individual who had received the diagnosis. Once referred to the project, potential participants were sent an information leaflet about the study then contacted

by telephone and a meeting was arranged for the researcher to answer questions and discuss the study.

The primary researcher had been employed in a senior position as a community mental health nurse in the field of dementia for more than 20 years, and had completed additional training as a counsellor. At the time of the study, she had been seconded to a university research fellowship, and was no longer in day-to-day contact with patients. The research team also included a senior researcher in health and social care who has a special interest in dementia, and a university professor of counselling with experience in qualitative research. All research data were collected by the primary researcher.

The main research participants were:

James, a 68 year old man, was the first person referred into the study. James had been married for 45 years, with three children, now all adults and living geographically distant from their parents. They had five grandchildren. James had run his own successful pharmacy business until retirement at 60 years of age. He had many hobbies and interests and was a devout Christian. He lived with his wife in a village near the major county town.

Beth, a 74 year old woman, had been married for 54 years, with two adult children both within travelling distance of one hour, and four grandchildren. She had been a school secretary until she retired at 60 years of age. Beth described herself as having many hobbies and interests. She lived with her husband in a quiet residential area of a major city.

Ian, a 79 year old man, had been married for 51 years, with two adult children who were both within travelling distance of one hour, and they had four grandchildren. Ian had been a GP

until he retired 18 years earlier. He had few hobbies that he was able to participate in because of his poor physical health. He and his wife had moved to a rural village on retirement.

Maggie, a 69 year old woman, had been widowed four years earlier. She had three adult children, one of whom lived with her, with the other two within a short distance. She had seven grandchildren. Prior to her retirement at age 65 years she had worked as a chef in a local hotel. She had few hobbies that she was engaged in. She lived in a small rural town.

Jenny, a 77 year old woman, had been married to her husband twice. They had divorced once, but they had never lost touch over the years and remarried two years ago. They had three adult children, two within travelling distance and one in South Africa. She was a secretary to a university Professor prior to her retirement at 65 years of age. She had few hobbies that she was able to engage in, because of physical disability. She lived with her husband in a small hamlet within two miles of a major city.

Involvement in the study was different and unique to each participant, and was determined by their life circumstances (see Table 1). In each case, an attempt was made to collect information from different sources and in different locations. The combination of sequential interviews, participant observation in settings that were central to the lives of participants, and contact with family members, generated data that would not have been available if, as in most previous research into the experiences of people with dementia, a solely interview-based approach had been employed. Participant observation allowed the researcher directly to witness conversations and interactions between the person with dementia, and other people in their life. These meanings of these observed actions were further explored during recorded interviews. The duration of the study meant that it was possible to spend time with key participants on their own, and with carers and family

members. The involvement in the study of family members and others, enabled a range of perspectives to be elicited. The regular presence of the researcher within each family, over a six-month period, facilitated a collaborative approach in which participants became active observers of their own experience. Finally, the use of a series of interviews made it possible for a process of ‘member checking’ to take place, in which tentative and emergent conclusions from previous interviews and observations could be explored with participants. These factors resulted in the construction of a rich data-set that included descriptions of action sequences over time, as well as more general meaning categories.

<Insert Table 1 about here>

Management of the data for this study was facilitated by the use of the NVivo Qualitative Data Analysis programme (Richards, 2005). Recordings of interviews were transcribed and data were then entered into the NVivo programme. Data analysis was informed by a Grounded Theory approach (Strauss and Corbin 1998). Memos and comments were added to the transcripts throughout the process of analysis using the ‘data bites’ feature. The transcriptions were then coded using the ‘free nodes’ facility, allowing for themes to emerge from the data. Recurring codes were grouped together utilising the ‘tree nodes’ facility with themes then being organised into coherent categories. A process of constant comparison between categories across transcripts was incorporated into this process. Theory was developed from the grouping of themes into main categories. On the fourth visit to each case study participant, the preliminary analysis was shared and the early formation of categories and concepts and discussion ensued and changes made accordingly until consensus was achieved. The primary researcher analysed the entire data set, with sections of data being co-analysed by other researchers with experience in qualitative methods. A range of methods

of data condensation and display were incorporated into the analytic process, including the construction of narrative case summaries, and visual diagramming of social networks, category structures, and action sequences.

The first case study (which lasted for 6 months) was analysed fully prior to the second case being recruited to the study. From the findings of the first case it was clear there were certain themes, for instance telling friends and family their diagnosis, which needed to be explored more fully in subsequent cases. This pattern of analysing cases and then exploring themes and issues from one to the next, continued with all subsequent case study individuals and families who became part of this project. A continuing iterative process of analysis was employed, based on tacking back and forth between transcripts and notes and listening again to recordings to revisit the actual spoken word. In the following sections, interview excerpts are identified in terms of the name of the informant, interview number, and line number within the transcript.

Findings

This section reports mainly on one aspect ('daring to tell') of the stories of five individuals as they moved beyond being told they had dementia and started 'living with' the conscious knowledge that they were formally diagnosed with this condition. In the report of the study as a whole, we discuss the experiences of the individuals and families as a 'journey' (Weaks 2006) that touched many aspects of their lives. A recurring theme through this journey was *struggling with the emotional impact*. The emotions experienced by the five case study individuals varied in their duration and intensity, but it is fair to say that all of them had to deal with feelings of dejection, distress, fear and devastation, leading, in some cases, to depression. Other emotions that were regularly described included uncertainty, bitterness,

loss and relief. Receiving a diagnosis of dementia sent participants into further emotional turmoil following a lengthy diagnostic process which in itself had evoked a myriad of emotions. Most of the participants described themselves as shocked and traumatised by what the doctor said to them during the disclosure of the diagnosis. The emotions experienced by participants were mainly seen as negative and painful. Emotional processing continued over the six month period and each individual processed their emotions in different ways. Some were more inclined to internalise their feelings and try to work through them on their own while others were more open to sharing these feelings and thoughts. Although the main findings reported in this paper focus on the issues and challenges arising from decisions whether or not to tell others about the diagnosis, it is essential to recognise that the context of this decision-making was far from constituting a calm and rational appraisal of possibilities. Instead, the decision to 'tell' was inextricably linked to on-going struggles around the containment and expression of feelings.

Daring to tell

For all participants, the act of telling others that they had been given a diagnosis of Alzheimer's disease was a very challenging and demanding task, which each person and their families tackled differently. There were degrees of telling, perhaps deciding to tell one or two close friends, or keeping the information exclusively in the family. There was also a timescale to the telling: some participants did not want to tell until their condition became more noticeable to others. Attitudes towards telling changed over the six month period: some people had moved from being secretive to being open; some had moved from secretive to less secretive; and others continued the same attitude from start to finish. However, what they did have in common was similar sets of reasons for both telling and not telling.

To tell or not to tell

There were many reasons given for not telling. They were private people and did not like to divulge their business to others: “I don’t like telling folk things like that” (Maggie: 3 83).

This reticence was clearly evident in four of the case study families, but Ian was different: “I think it is a good idea [to tell people]... och yes, I mean you don’t hide things these days do you?...no we are not whispering about it” (Ian 2 376-423). Ian explained that today’s society was much more open and accepting with no need to hide away such a diagnosis, whereas the others felt that it was something to keep to themselves, or at the very most, within the family. Another reason given not to tell was trying to protect people from bad news until absolutely necessary: “I thought there is no point in saying anything until...later on is in plenty of time, there is no point in worrying them all starting now you know.” (Beth: 2 43).

Sometimes the reluctance to tell appeared to serve the function of helping to preserve an intact self: “I would prefer to think I am still a bit normal... no doubt it will worsen so I feel that I just should be quiet and wait until it becomes obvious” (Jenny: 1 185; 5 77). By telling people, Jenny felt that she would be admitting to both them and herself that she was no longer normal. James was also keen to delay having to tell until people noticed themselves. There was also a sense of shame: “for me to say that I have Alzheimer’s would be, well, I wouldn’t own up to it ...I wouldn’t like to mention it to anybody actually and wouldn’t you be the same?” (Jenny: 1 151; 2 185). This thinking was related closely to the fear of being judged by others, and also to anxiety around relationships being threatened: “well if I told a lot more people I would think that relationships would change, but I haven’t told that many people...it’s a stigma...I would never dream of telling the lady next door” (Jenny: 5 73; 61). Feeling stigmatised by the diagnosis was a barrier to telling people, along with the fear of negative reactions that might be precipitated: “I wouldn’t want people to think I was

Doolally...I think that could be disastrous” (James: 6 286).

Something that troubled most of the participants was the lack of control they had if they told. They knew that it was inevitable that some people, when they found out, would then tell others. There was a need for trust and confidentiality to be conditions of a disclosure, with the consequence that the diagnosis would be shared “only to people I know will be circumspect in passing it on” (Jenny: 5 247).

These were the main reasons why people were reluctant about disclosing their diagnosis to others, especially when it stretched beyond the boundaries of the family. Maggie was the only participant who did not want all of her adult children to know.

The reasons for telling the diagnosis were also diverse, with some unique to one family while other reasons were shared. There was a much stronger feeling, especially among the female participants for not telling, or limiting the telling to family rather than telling their wider social network. The main motivation for telling the diagnosis was to offer an explanation to people who might have observed changes in the person’s behaviour or way of being. This was certainly the case for both men. “I just said this memory etc., isn’t working. I have seen the Consultant and the brain scan says early stages of Alzheimer’s, so if I start to stutter it is not the whisky!” (Ian: 3 135). James was keen for people to know that he was not responsible for any changes in functioning and was worried that people might think him discourteous, “I feel it is quite important in the sense if they notice that I am doing something that I ought not to be doing, or if I have forgotten something they know it is not deliberate, but something which I have no control over” (James: 5 15).

The worry that the condition may be genetically inherited was a motivating factor for telling the family, to alert them of such a possible danger. Indeed, one daughter did go to her GP to check out if this was so once she realised her relative had this diagnosis. Another reason for telling was the stress felt in trying to hold it in: “it’s more stressful than it should

be and...I think where the stress of it has come is trying to keep everything on the surface going while things are just not really quite the same” (James: 2 339 & 355). The realisation that it is also stressful for the partner to be maintaining the façade as well, and the dawning awareness that his wife was trying to shield him, “you have been protecting me,” (James: 2 333), from people finding out, encouraged James to tell people about his diagnosis. This happened gradually over the six months, whereas Ian had told people from the start, feeling it was best to be open about things. Jenny became happier to tell people towards the end of the six month period. Both Beth and Maggie, however, were as reluctant to tell at the close of the project as they had been at the beginning.

Who should tell and who to tell

As can be seen from the above section there were more reasons given to keep quiet than to disclose the secret. But whose secret was it? Debate about who has ‘ownership’ of a diagnosis has been highlighted within the ‘rights’ movement, where it is argued that the diagnosis always belongs to the ‘patient’. At the time of diagnosis, without exception, the next of kin of the participant was present at the time of the diagnosis-giving, so although the diagnosis was made ‘on the patient,’ it was given to both patient and family by the diagnosing Consultant or Specialist Registrar. The various families who participated in the study processed this whole area of who should tell differently, and there was more weight put on tacit contracting rather than on overt discussion between the diagnosed person and the family member about who should tell the diagnosis.

There was no discussion between Ian and his wife around who should tell. He told the family: “the family all know... I just said well I’ve got this and it might last for years...we’ve told them, ...so that’s it.” (Ian: 2 231). His wife had taken the opportunity to tell a gathering of friends, ten in number:

“We were out for lunch last Sunday ...I just said I think perhaps you had better know that Ian has been diagnosed as Alzheimer’s. We have to accept it, our family and our grandchildren [have to accept it] and that’s it. So it’s better to do that I thought than hedge because I think they suspected that things were not just quite as they should be” (Ian-Joan: 1 364).

Although there had been no prior discussion between Ian and Joan on this issue, there was no discord about who told what to whom, and they were both pleased that their family and friends knew. This was not so with all of the participants: Ian and Joan were the only ones who told everyone as soon as they could following diagnosis. By contrast, James started off wanting to keep the diagnosis within the family. Again, nothing was discussed, but he took it for granted that his wife would tell the family, “I don’t think I ever discussed it with them ...Mary has mentioned it to the family” (James: 1 199). James was reluctant to disclose his diagnosis even to the family and admitted, “I have a tendency if something is unpleasant to try and avoid or how can I put it...avoid or run away from it...I am a head in the sand sticker!” (James: 2 202-210). James took the view that he would have no objection to his wife telling people, and the decision was made to tell people on a ‘slow release’ basis rather than ‘broadcast to everybody’. Following that decision to keep their secret less private, James decided to experiment with telling people himself, first of all telling the car insurance firm to check that he was not breaking the law, then telling someone he met from the Church choir. Both of these encounters were successful, and while James did not find it easy to tell, he was amazed at the positive and supportive responses that he got.

As his experiment had been successful (he was still a scientist), James was prepared to repeat it. He wanted to inform his Pastor, for two reasons. Out of respect he did not want the Pastor to hear this news from others and he wanted to make sure that the Pastor knew why he might not be so willing to take on extra Church duties as he would have normally done.

He continued to tell and informed many key people in his social network. He tried to weave it naturally into his conversation: “we were just drinking coffee together and I said you would maybe realise it but I am an Alzheimer’s victim, sort of thing, but it doesn’t make any difference so there we are” (James: 4 39). He chose who he told in the various clubs of which he was a member, confident that the news would spread and he would not have to tell everyone personally. Initially, he just could not envisage how he could possibly tell his friends that he had a diagnosis of Alzheimer’s disease and spent many hours questioning, and trying to find an answer to that puzzle. He had gone from being secretive and trying to run away from it to embracing the challenge and being very positive about it all. Over the six months, it was James’s attitude to telling that changed most.

The changes in the attitude of the women in the study were less dramatic. Jenny had moved from not wanting to own up to having Alzheimer’s disease to thinking that she was “not unhappy about letting it be known because I feel, well it’s better to talk about it and let everybody else know what is going on,” (Jenny: 1 399), then shifting back and forward between the two positions until she became more comfortable with selective telling later on. Beth restricted the telling to her immediate family, “just the family, my daughter, son and them [grandchildren], that’s all, nobody else” (Beth: 5 111) and she left the telling to her husband, and for the full six months of our contact Beth did no telling. The primary researcher never heard her utter the words Alzheimer’s disease but she referred all the time to ‘it’. When questioned about whether she had ever discussed the subject with her husband, Beth replied, “well we are sort of into a routine and he knows that I’ve got it and I know he knows I’ve got it and we are just ordinary, we don’t bother, just forget it if we can” (Beth: 5 112).

The situation was very similar with Maggie, and although she would not tell her sons she did allow her daughter Julie to tell a brother and sister-in-law, whom she had a close relationship with, on her behalf.

Telling someone that you had been given a diagnosis of Alzheimer's disease was clearly a very difficult task and one that provoked much discussion with the people in the study and their families. At times families were united in the way that they tackled the telling, and at times it was a cause of great stress and concern between them.

The implications of telling

There were both positive and negative implications of telling. The positive implications were that needs could be highlighted to friends: "we don't want sympathy, and we want their friendship ... and we don't get sympathy from our family either, we get support, they treat their father the way they have always treated him and that's the way it's got to be," (Ian: 1 450). James experienced many offers of help, with driving, with friends calling to remind him that he had meetings to attend with them, and there was a concern for him within his circle of friends. He also experienced considerable relief when he told his Pastor: "there was a load on my back and he took some of it off," (James: 3 898). In sharing his concern he was able to unburden.

There were also negative implications and some were experienced by Ian who had been open about his diagnosis from the beginning, when two of his friends started to treat him in a patronising manner. While the increased concern and assistance offered to James was perceived as helpful by both him and his wife, it could just as easily have been perceived as a loss of autonomy. The females in the study did not share many of the implications of telling, simply because they rarely told, and then only to their close relatives.

The implications of not telling

There were implications for not telling, most of which appeared to be negative. One of the implications experienced by Beth was that of isolation and although her husband knew and worked hard to help her keep her secret, she acknowledged that: “we are on our own, just George and I” (Beth: 6 23). Even with George there, and referring to them both as we, what came across was that she saw herself as being on her own with this diagnosis even although she was with George and the family knew: “well they know, but we didn’t really discuss it.” (Beth: 3 86).

It is difficult to access appropriate informal support networks when there is a not-telling rule. Another implication of not telling is that people would notice anyway and draw their own conclusions: “if I didn’t tell people they would think I was drunk” (Ian: 2 87); “people think that they can’t make arrangements with you, because you don’t keep it,” (James: 2 331). Trying to keep everything the same without telling was also felt to be a strain by James and Mary, and keeping the secret made the situation even more stressful than it needed to be. Maggie never did tell. The implications of not telling would seem to have a mainly negative effect on the person with the diagnosis and the fear of the reaction of others had been what had frequently stopped them. For those who decided to tell, the reactions of recipients had mainly been favourable although at times perhaps less favourable than had been expected.

Reactions to the telling

There were mixed reactions to people being told that their relative/friend had Alzheimer’s disease. Two people felt that their situation was being minimized by family members and although they recognised that it had been done from the best intentions it had not always been

useful. When asked how people told had reacted, Beth commented: “how have they taken it? Well my son’s wife is a nurse and what he said was it’s not as bad as you might think” (Beth: 2 291). As a result, Beth’s son, did not discuss the matter further with his mother and so did not learn how bad she thought her condition was for her.

Jenny experienced a very similar situation with a phone call from her son: “I remember once talking to him on the phone, he lives in Edinburgh, and I said to him, I am forgetting a lot of things these days, and he said don’t worry Mum, I forget too, and I thought oh my goodness ... but I suppose it was just a natural reaction” (Jenny: 411). Jenny’s fear at that time was that her condition was genetically inherited and she thought that this was her son starting to experience the first signs of Alzheimer’s disease as well.

Even although Ian’s family was under instruction from both parents to accept it, his son found it very difficult initially: “our son wasn’t very willing to accept it, but he does now, he realises now...I think he saw that there was a change” (Ian: 2 286). The rest of his family conformed more quickly, with one granddaughter finding lots of new information on the internet which she printed for her grandparents to read, and this made them feel very proud.

James’ family were not local and they were told on the phone by their mother and they were upset, feeling helpless because of the distance between them, but up until the end of the study they had still not discussed it with their father, and neither had he sought to discuss it with them. His friends, however, expressed sadness, but reassured him that it would not make any difference: “there were no flames or anything...they just went on as usual, nobody seems to worry about whether I have got all my full marbles or not you know” (James: 4 27 & 43). James got the most positive response from his Pastor

“He was exceedingly good, he knelt down and prayed with me and I felt that was a very good thing. I think that it released a feeling of tension, that I had actually told somebody and they were sympathetic to me, and everything was more or less as

before except that he knew...I felt a great sense of relief at that point that I had told somebody and getting it off my chest...it wasn't a shut out process like you cannot come to Church anymore...I think he understands" (James: 3 35)

He was able to have a good discussion with his Pastor about how it felt to have this diagnosis and this was an opportunity not afforded to him by anyone else.

Reactions to the telling were mixed, with some surprises, some disappointments, and in some cases it seemed to be no big deal. For James and his Pastor, it was an intimate moment in their relationship. For Maggie there was no reaction because there was no telling. But in all of the activity that was the telling, the only person who was prepared to discuss the implications of the diagnosis with the person was the Pastor.

It's good to talk

The act of telling is different from talking or discussing issues around the diagnosis. Telling demanded little of the listener other than an acceptable, appropriate response, while talking or discussing raised difficult issues. For their own different reasons most of the families found it difficult to discuss the diagnosis with each other: "you tend to keep all the talk about it in the family, they know you have got it but ignore it, so it is a help [to talk about it]" (Beth: final interview 140). At the same time, all participants in the study commented on how beneficial it was to talk about their thoughts and feelings following their diagnosis within the research context. They observed that dementia was a subject that people shied away from. All of them receive regular visits from community mental health nurses, and they all observed that even their nurses tended to concentrate on problems and effects of medication rather than have a discussion about their thoughts and feelings about the diagnosis. Nobody, it seemed, ever brought it out in conversation. "I never mention it, I never bring it up, you [the researcher] are the only one who brings it up" (Jenny: 2 335). Yet there was a realisation

of the need to talk: “it is very good to talk to somebody, you feel I must discuss this with somebody you know” (Beth: 4 240). Within the research project, it was possible to have a conversation that they might otherwise be denied, as in the following interview dialogue

Researcher: Right so you are able to speak about things that you are not able to speak about anywhere else

Beth: That’s it exactly. You see George is with me all the time and you come in and it is a different conversation ... prior to that you are in a sort of vacuum” (Beth: 4 5 & final interview 148)

Ian raised the point that it was not just that people did not want to discuss things but that they were uninformed and would shy away from talking about something that they did not know about. He felt that talking about it “is good for you, you know we were talking and ordinary people, they don’t know” (Ian: final interview 7). Talking to professionals rather than lay people who did not know about the subject seemed preferable to some participants and they cited the need for being understood as important, and being able to talk about it helped to minimise the associated problems: “it’s better to discuss it with you than with anybody who doesn’t have any experience at all...it made it seem less of a problem” (Jenny: final interview 93). Being able to express and share feelings was also something that the participants found to be important: “to be able to talk about it, we were able to express our own feelings and then talk about it together.” (James-Mary: final interview 69).

Although the potential value of talking through their thoughts and feelings was highlighted by all participants, only James’ Pastor had been able to offer that kind of experience. Being part of the research project had led to the participants being enabled to discuss these thoughts and feelings in a different way and they felt that this: “enabled a communication channel to be opened up that wasn’t possible before,” (Jenny-Ron: final

interview 219), with each other, and they were able to discuss issues pertaining to their diagnosis that they had not previously been able to do. Being able to talk with families, friends, or professionals was a crucial factor in the emotional processing and also in the shaping of a different identity, and indeed in coming to terms with and working towards acceptance and integration. Not being able to talk inhibited this process and resulted from participants having to process their emotions internally with little opportunity to have these emotions validated or indeed invalidated.

Discussion

The findings of this study need to be interpreted with caution. Only a small number of participants were involved, drawn from a culturally homogenous group. All participants had previously retired from employment, so were not faced by the requirement to explain their health status to employers or work colleagues, and all lived within a family context while four of the five were in stable long-term relationships. It is clear that a more comprehensive understanding of the issues and challenges associated with the task of telling others about a diagnosis of dementia will only be accomplished following further research in a range of social settings. Despite these limitations, participants in the study demonstrated a high level of commitment to the project, and talked openly and honestly about a range of personal concerns. In addition, the study did not depend solely on individual interviews, but was able to draw on a range of sources of information.

There are two main conclusions that can be proposed, with due tentativeness, on the basis of the findings of this study. First, there are many different ways in which people who have received a diagnosis of dementia, and their families and carers, deal with the task of telling others about the diagnosis. In this respect, the cultural homogeneity of the study sample is an advantage. Even within a set of people who share a common cultural identity

and way of life, there are some who choose to be very open about their diagnosis, and others who opt to be highly secretive. These strategies for telling/not telling appear to be rooted in long-established personality, family and relationship dynamics. Although all of the participants took the same issues into account (who to tell, the consequences of telling, etc.), they tended to resolve these issues in different ways. In these respects, the findings of the present study reinforce the conclusions of previous research that has explored the experience of ‘telling others’ in the period following a diagnosis of dementia (Langdon *et al.* 2006; McRae 2007; Preston *et al.*, 2007; Werezak and Stewart 2002). Taken together, what these studies reveal is a diversity of positions and strategies around the activity of ‘telling’. The findings of the present study suggest a number of factors that appeared to shape the process of telling. Prior to receiving the diagnosis, the participants in the study who found it hardest to tell, seemed to have had lives that were characterised by anxiety around self and relationships, a somewhat restricted social life, and tensions within close family relationships. By contrast, the participants who found it easier to tell were more emotionally resilient, and could draw on a wider range of social resources. Gender and occupational identity were also factors that shaped the lived experience of telling. .

The second main conclusion of the study is that people who have received a diagnosis of dementia *want to talk about how this makes them feel*, whether or not they decide to disclose information about their condition to family and friends. The context of the study, in which participants spent many hours in conversation with a skilled listener and counsellor, largely talking about the barriers to talking that they experienced in their everyday lives, allowed this phenomenon to emerge with some force. Even though many hours of interview were recorded, and even though participants were regularly asked about the emotional support they received, only one clear-cut episode of facilitative listening was documented (the meeting between James and his Pastor). This finding was unexpected. The design of the

study was partially driven by an intention to explore the ways in which people with dementia engaged with, and were empowered by, conversations with health professionals, in relation to the tasks of coming to terms with their diagnosis, and beginning to build relevant support networks within their communities. We found no evidence that such conversations occurred for the participants in the study. It is still hard for many health professionals to talk about dementia (see, for example, Phillips et al., 2012), and it may be that this reticence may contribute to the difficulties that their patients experience in disclosure of their diagnosis within their social circles.

The experiences of the people who took part in this study confirm that the activity of telling comprises a key element in the process of coming to terms with a diagnosis and co-constructing a different sense of self. The findings reported in the present study are consistent with theoretical perspectives on the nature of self in dementia (Sabat, 2001; Sabat and Collins, 1999) Sabat and Harre (1992).describe a ‘self²’, comprising the publicly presented repertoire of a multiplicity of selves which are revealed in everyday interpersonal interactions, and are constantly being co-constructed through talk. In the period immediately following a diagnosis, the process of ‘telling’ represents the arena within which this social self begins to be re-negotiated. However, what needs to be told is threatening for both speaker and hearer, and has the potential to trigger strong emotions in both participants. In this context, it is helpful to be able to rehearse the ‘telling’ with an interlocutor, such as a doctor, nurse, pastor or counsellor, who does not feel threatened by the story that is being told. This type of conversation has the potential to function as a bridge to parallel conversations with friends and family members. The findings of our study suggest that participants intuitively recognised this, and wanted it. In this study, all participants reported some kind of difficulty with the act of ‘telling’, regardless of prior coping strategies or quality of social support. This model makes it possible to understand the interaction between sense of

self, emotion and relationship, in this situation. The severity of threat and disruption to the core sense of self, arising from a diagnosis of dementia, is experienced at a bodily level in the form of painful emotions. The way forward, in terms of developing a revised sense of self, requires being able to share these emotions with others. If such conversations are inhibited by shame and stigma associated with the condition, and fear of how the other will respond, it is possible that unexpressed negative emotions will become an on-going aspect of the person's inner world (in the form of depression), and inhibit the capacity of the person to engage in collaborative problem-solving. An important practical implication of this model is to highlight the necessity for practitioners such as nurses and GPs, who are in regular contact with people who have received a diagnosis of dementia, to be willing to respond to 'empathic opportunities' presented by patients with dementia (Eide *et al.* 2004; Mercer *et al.* 2005). Høigaard and Mathisen (2008) and McLeod and McLeod (2011) have presented frameworks for the delivery of brief, situated counselling responses that can be incorporated into routine practice. Steenman *et al.* (2006) recognise the pivotal role that nurses can potentially fulfil in this area. Weeks, McLeod and Wilkinson (2006) and Weeks, Johansen, Wilkinson and McLeod (2010) have outlined some of the ways that these ideas can be implemented within the field of dementia care. To support such innovatory practice, it would be valuable to carry out longitudinal research to examine the extent to which empowerment to tell in the period immediately following a diagnosis of dementia, contributed to a process of constructive readjustment of self and relationships, that might serve to maintain supportive relationships at later stages in the course of the condition. Our findings suggest that, although the act of 'telling' appears to be a generalised issue, it is likely that in a larger sample it should be possible to identify different pathways of disclosure associated with the personal attributes and social contexts of those who have received a diagnosis.

References

- Bunn F., Goodman C., Sworn K., Rait G., Brayne C., Robinson L., McNeilly E., and Iliffe S., 2102. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Medicine/Public Library of Science* **9** 10 e1001331. doi:10.1371/journal.pmed.1001331
- Cayton, H. 2004. Telling stories: choices and challenges on the journey of dementia
Dementia: The International Journal of Social Research and Practice **3**, 1, 9-17.
- Clare, L. 2002. We'll fight it as long as we can: coping with the onset of Alzheimer's disease.
Ageing and Mental Health, **6**, 2, 139-148.
- Clare, L. 2003. 'I'm still me': living with the onset of dementia. *The Journal of Dementia Care* (March/April), 32-35.
- Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M. And Scheltens, P., 2006.
Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis. *Ageing and Mental Health*, **10**, 5, 525-53
- Dewing, J. 2002. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia: The international journal of social research and practice*, **1**, 2, 157-171.
- Eide, H., Frankel, R., Haaversen, C, Vaupel, K., Graugard, P. and Finset, A. 2004. Listening for feelings: identifying and coding empathic and potential empathic opportunities in medical dialogues. *Patient Education and Counseling*, **54**, 291-7.
- Elson, P. 2006. Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer's disease? *International Journal of Geriatric Psychiatry* **21**, 419-425.
- Frank, A. 1995. *The wounded storyteller*. The University of Chicago Press, Chicago.
- Harris, P. B. and Sterin, G. 1999. Insiders perspective: defining and preserving the self of

- dementia. *Journal of Mental Health and Aging*, **5**, 3, 241-256.
- Høigaard, R. and Mathisen, P. 2008. Informal situated counselling in a school context. *Counselling Psychology Quarterly*, **21**, 293–299.
- Langdon, S.A., Eagle, A., and Warner, J. 2007. Making sense of dementia in the social world: A qualitative study: *Social Science & Medicine* **64**, 4, 989–1000.
- McLeod, J. and McLeod, J. 2011. *Counselling skills. A practical guide for counsellors and helping professionals*. 2nd edn. Open University Press, Maidenhead.
- MacRae, H. 2007. Making the best you can of it: Living with early stage Alzheimer's disease. *Sociology of Health and Illness*. Vol. 30 No.3, 396-412
- Mercer, S.S., McConnachie, A., Maxwell, M., Heaney, D. and Watt, G.C.M. 2005. Relevance and practical use of the Consultation and Relational Empathy (CARE) measure in general practice. *Family Practice*, **22**, 328-334.
- Muecke, M. A. 1994. On the evaluation of ethnographies. In: J. M. Morse, ed. *Critical issues in qualitative research methods*. Sage: Thousand Oaks
- Pearce, A., Clare, L. and Pistrang, N. 2002. Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, **1**, 2, 174-192.
- Phillips, J., Pond, C. D., Paterson, N. E., Howell, C., Shell, A., Stocks, N., Goode, S. M. and Marley, J. 2012. Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *British Journal of General Practice*, **62**, 601, e546-e553 (8)
- Phinney, A. 1998. Living with dementia from the patient's perspective. *Journal of Gerontological Nursing*, **24**, 6, 8-15.
- Phinney, A. 2002. Fluctuating awareness and the breakdown of the illness narrative in dementia. *Dementia: The International Journal of Social Research and Practice*, **1**, 3, 329-344.

- Pratt, R. and Wilkinson, H. 2001. Tell me the Truth. The effect of being told the diagnosis of dementia from the perspective of the person with dementia. *Mental Health Foundation*, London
- Preston, L. and Bucks, R.S. 2007. Investigating the ways that older people cope with dementia: a qualitative study. *Aging & Mental Health*, **11**, 2, 131-43
- Richards, L. 2005. *Handling qualitative data: a practical guide*. London: Sage.
- Sabat, S. R. 2001. *The experience of Alzheimer's disease: life through a tangled veil*. Blackwell, Oxford.
- Sabat, S. R. and Collins, M. 1999. Intact social, cognitive ability, and selfhood: a case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*. **14**, 1, 11-19.
- Sabat, S. R. and Harré, R. 1992. The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, **12**, 443-461.
- Steenman, E., Dierckx, B., Godderis, J. 2006. Living with early stage dementia: a review of qualitative studies. *Journal of Advanced Nursing*, **54**, 6, 722-738
- Strauss, A. and Corbin, J. 1998. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd ed. London: Sage.
- Weeks, D. 2006. Living within a limited freedom: the perceptions and experiences of early dementia from the perspectives of people with the diagnosis and the diagnosticians. Unpublished PhD thesis, University of Abertay Dundee.
- Weeks, D., McLeod, J. and Wilkinson, H. 2006. Dementia. *Therapy Today*. **17**,3, 12-15.
- Weeks, D., Johansen, R., Wilkinson, H., and McLeod, J. 2010. Training nurses to deliver post-diagnostic dementia support. *Healthcare Counselling and Psychotherapy Journal*. **10**, 3, 26-31
- Werezak, L., and Stewart, N. 2002. Learning to live with early dementia. *Canadian Journal*

of Nursing Research. **34**, 1, 67-85.

Wilkinson, H. and Milne, A. 2003. Sharing a diagnosis of dementia: learning from the patient's perspective. *Ageing & Mental Health*. **7**, 4, 300-307.

Wolverson E.L., Clarke C ., and Moniz-Cook E. 2010. Remaining hopeful in early-stage dementia: A qualitative study, *Aging & Mental Health*. **14**, 4, 450-60